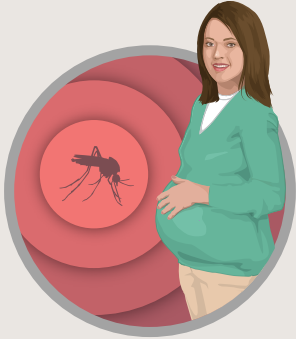


# US ZIKA PREGNANCY REGISTRY

## Pediatric Healthcare Providers: How to Participate



**Zika virus infection during pregnancy has been linked to [adverse outcomes](#), including pregnancy loss and microcephaly, absent or poorly developed brain structures, defects of the eye, and impaired growth in fetuses and infants. Despite these observations, very little is known about the risks of Zika virus infection to infants. More information about the timing, absolute risk, and spectrum of outcomes associated with Zika virus infection among infants is needed to direct public health action related to Zika virus and guide testing, evaluation, and management of pregnant women and infants exposed to Zika virus.**

## US Zika Pregnancy Registry

To understand more about Zika virus infection, CDC established the US Zika Pregnancy Registry and is collaborating with state, tribal, local, and territorial health departments to collect information about pregnancy and infant outcomes among pregnant women with laboratory evidence of Zika virus infection and their infants. The data collected through this registry will provide more comprehensive information to complement notifiable disease case reporting and will be used to update recommendations for clinical care, to plan for services for pregnant women, children, and families affected by Zika virus, and to help prevent Zika virus infection during pregnancy.

### How to Participate

CDC and state, tribal, local, and territorial health departments request that pediatric healthcare providers participate in the US Zika Pregnancy Registry by:

1. Identifying and reporting suspected congenital Zika virus exposure to their state, tribal, local, or territorial health department for possible testing; you may contact [zikapregnancy@cdc.gov](mailto:zikapregnancy@cdc.gov) to receive US Zika Pregnancy Registry State Health Department contact information.
2. Collecting pertinent clinical information about infants born to women with laboratory evidence of Zika virus infection or infants with congenital Zika virus infection.
3. Providing the information to state, tribal, local or territorial health departments or directly to CDC registry staff if asked to do so by local health officials.
4. Notifying state, tribal, local, or territorial health department staff or CDC registry staff of adverse events (e.g., perinatal or infant deaths).

### Who to Report to the Registry

Infants are eligible for inclusion in the US Zika Pregnancy Registry if they are born in a US state or territory (with the exception of Puerto Rico) and are either: 1) born to a woman with laboratory evidence of possible Zika virus infection (regardless of whether she has symptoms, or 2) infants with laboratory evidence of possible congenital Zika virus infection (regardless of whether they have symptoms).

[www.cdc.gov/zika](http://www.cdc.gov/zika)



**U.S. Department of Health and Human Services**  
Centers for Disease Control and Prevention

Some infants who meet the above criteria will have been identified prenatally and reported to the health department in accordance with applicable state, tribal, local and territorial laws supporting notifiable disease surveillance. However, pediatric healthcare providers may also identify previously unrecognized infants with congenital Zika virus infection or with periconceptual, prenatal, or perinatal exposure. Information about these infants should be reported to the state, tribal, local, or territorial health department and are eligible to be included in the US Zika Registry. The US Zika Pregnancy Registry will collect supplemental surveillance information from routine medical care of women through pregnancy and infants through the first year of life.

Healthcare providers practicing in Puerto Rico should report information to the Puerto Rico Zika Active Pregnancy Surveillance System (ZAPSS) rather than to the US Zika Pregnancy Registry.<sup>1</sup>

## How To Report to the Registry

- Healthcare providers should contact their state, tribal, local, or territorial health department to arrange for laboratory testing for Zika virus infection if the infant meets the clinical criteria for testing as outlined in the [CDC guidelines](#).
- Healthcare providers can contact CDC (call CDC's Emergency Operations Center watch desk at 770-488-7100; email [ZikaPregnancy@cdc.gov](mailto:ZikaPregnancy@cdc.gov); or fax 404-718-1013) to discuss information on infants suspected of having congenital Zika virus infection. If healthcare providers contact CDC for clinical consultation, Registry staff will ensure that state, tribal, local, or territorial health departments are promptly notified.

## How the Data are Collected

Depending on the preference of the state, tribal, local, or territorial health department, either health department staff or CDC Registry staff will contact clinicians caring for infants with congenital Zika virus exposure or infection for data collection.

CDC is requesting the collection of clinical information in identifiable form as a public health authority. As defined in the Health Insurance Portability and Accountability Act (HIPAA) and its implementing regulations, Standards for Privacy of Individually Identifiable Health Information (45 CFR § 164.501)] ("Privacy Rule"), covered entities (e.g., healthcare providers) may disclose protected health information without patient authorization to a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease (42 CFR 164.512). Data to be collected include clinical information pertaining to results from evaluation and testing conducted at birth, and clinical/developmental information from the infant through the first year of life. As established in the HIPAA Privacy Rule (45 CFR 164.528), individuals have the right to request from covered entities (i.e., you, the healthcare provider) an accounting of the disclosures of their protected health information.

You may wish to use the fact sheet for [pregnant women](#) to let your patients know how their information is being used. This fact sheet also contains information on the Assurance of Confidentiality that CDC has obtained. The Assurance is a formal confidentiality protection authorized under Section 308 (d) of the Public Service Act. Under this Assurance, identifiable information about your patient and the care you provide can only be used to better understand Zika virus infection during pregnancy and its outcomes. CDC cannot share it with anyone without your permission and your patient's permission, even if an official of the court, the government or law requests it.

## More Information about Zika

For more information, visit CDC's website [www.cdc.gov/zika](http://www.cdc.gov/zika). If families would like to speak to someone about a possible Zika virus infection or diagnosis during pregnancy, MotherToBaby experts are available to answer questions in English or Spanish by phone, email, or chat: [www.MotherToBaby.org](http://www.MotherToBaby.org). The free and confidential service is available Monday - Friday from 8am - 5pm (local time).

<sup>1</sup> Puerto Rico is establishing a separate Zika Active Pregnancy Surveillance System (ZAPSS)

## CDC Guidance Materials

1. Interim Guidance for Health Care Providers Caring for Women of Reproductive Age with Possible Zika Virus Exposure – United States, 2016 (Apr. 1, 2016) [http://www.cdc.gov/mmwr/volumes/65/wr/mm6512e2.htm?s\\_cid=mm6512e2\\_e](http://www.cdc.gov/mmwr/volumes/65/wr/mm6512e2.htm?s_cid=mm6512e2_e)
2. Interim Guidelines for Healthcare Providers Caring for Infants and Children with Possible Zika Virus Infection – United States, February 2016 (Feb. 19, 2016) <http://www.cdc.gov/mmwr/volumes/65/wr/mm6507e1.htm>
3. Zika Virus: Collection and Submission of Fetal Tissues for Zika Virus Testing <http://www.cdc.gov/zika/hc-providers/tissue-collection-submission.html>
4. Collection and Submission of Body Fluids for Zika Virus Testing <http://www.cdc.gov/zika/hc-providers/body-fluids-collection-submission.html>